

Achalasia Action — MP Campaigning Primer (Supporter Brief)

Use this 2-page note to brief your MP during a surgery meeting.

1) A simple script for your surgery meeting

- Introduce yourself (name, town, connection to achalasia).
- What is achalasia? (rare disease that affects the oesophagus; principal symptoms and issues; affects est.6000 people in the UK).
- Your story in 3 lines (symptoms, how long it took, one impact on daily life – try to keep it local).
- At least two facts (pick from the list below).
- At least one clear ask (choose one from section 4).
- Suggest asking a question in Parliament (see section 5).
- Recommend that they contact Achalasia Action (at jack.eddy@achalasia-action.org) for more information and/or ideas for influencing government.

2) Why this matters?

- Only around 6,000 people in the UK live with achalasia - but most face years of misdiagnosis and delay.
- Delays mean malnutrition, emergency attendances, and severe distress for patients and families.
- A few changes in the NHS and wider health system would dramatically shorten the journey to diagnosis and care.

3) Headline findings from our UK patient-led report (publishing 30 September)

- 28% waited over 3 years for a diagnosis (35% less than a year, 37% 1-3 years); the longest recorded wait was 17 years.
- 30% received 4 or more wrong diagnoses (commonly reflux, anxiety or an eating disorder) before achalasia was recognised.
- Only 61% received the gold-standard test (oesophageal manometry) - leaving a postcode lottery in diagnosis.
- Women are 13 percentage points more likely than men to wait over 3 years and are more often labelled with psychological explanations.
- 70% reported severe psychological distress during the diagnostic journey; 74% rated the physical impact at 7–10/10.
- 16% paid privately to bypass NHS delays - deepening inequality.

4) What you can ask your MP to do (concrete actions)

1. Back a **national diagnostic pathway** for achalasia (and similar rare GI disorders) with clear time targets from GP referral to testing and treatment.
2. Press for **GP decision-support prompts** in EMIS/SystemOne for persistent dysphagia, so achalasia is considered and referred appropriately.
3. Secure **high-resolution manometry capacity** in every region, with published waiting-time standards and equity monitoring.
4. Set **communication and after-care standards**: face-to-face diagnosis, written care plan, named contact, and mental-health signposting.
5. Tackle inequality: require **sex-disaggregated diagnostic data** and **bias training** for frontline services where dismissal is common.
6. Ensure achalasia features in the **next UK Rare Diseases Framework refresh (post-2026)** with diagnostic-delay metrics.

5) Things your MP can do in Parliament

- **SIGN EDM 2770 - Rare Disease Day and Achalasia**
- Table **Parliamentary Questions** asking the Government about
 - a) manometry capacity and waits
 - b) GP system prompts
 - c) national pathway work.
- Support or lead a **Westminster Hall debate** on diagnostic inequality in rare GI conditions, citing Achalasia Action's report.
- Write to the **Secretary of State** and NHS England to request a plan for a national achalasia pathway and capacity for manometry.
- Ask the local **Integrated Care Board** and trust for local data: time to manometry; referrals; and equality breakdowns.
- Meet Achalasia Action to discuss next steps and connect officials with our clinical advisers.

6) After the meeting: quick follow-up

- Email a thank-you the same day, restating your one ask and attaching the report summary link.
- Tell Achalasia Action that you met with your MP on social media – make it public but keep it respectful (no matter how it went).
- If your MP's office sends a follow up to you, tell us the outcome so we can track progress across constituencies.

7) Practical tips for supporters

- Be specific and local if you can (e.g., "Our trust doesn't offer manometry - the nearest is 60 miles away").
- Use the data to showcase the **systemic problems** involved with Achalasia. Beyond that, stick to your lived experience; don't share medical advice.
- If you feel uncomfortable or nervous, bring a friend or relative with you.
- Time is short in surgeries - keeping to the script helps you get a clear outcome.

- If asked for more information, note it and say Achalasia Action will follow up.